Perceptions of Multiple Sclerosis Care During the COVID-19 Pandemic: Examining Real-world Evidence From Patients and Providers

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INTRODUCTION

Revolutionary advances in multiple sclerosis treatment options have transformed outcomes by slowing disease progression, minimizing relapses, preserving brain function, and improving the quality of life for people living with this chronic, debilitating disease.[1,2] Shared decision-making (SDM) plays a key role in harnessing these advances by aligning the latest evidence and patients' goals, preferences, and values to develop a personalized and optimized care plan.[3] However, many factors, including time constraints and barriers to communication, pose challenges to SDM and limit the engagement of patients in treatment decision-making in clinical practice. In addition, the COVID-19 pandemic has transformed how MS providers engage with their patients and poses new challenges in adherence to treatment and disease monitoring in the setting of social distancing.[4]

This initiative aimed to assess and compare patients' and providers' perceptions of treatment goals and challenges, aspects of care about SDM, and the impact of COVID-19 on treatment plans to identify alignments and discordances that may be addressed to improve MS care.

METHODS

Between July 2021 and October 2021, surveys were administered to MS providers (n = 22) and MS patients (n = 126) from 9 MS clinics in the US in the context of a collaborative educational program. The surveys included tethered items that asked providers to estimate their patients' preferences and perceptions regarding their MS care in order to uncover potential alignments and discordances. Surveys were administered before and after the educational activity in order to also assess the impact of the activity on goal setting in order to improve outcomes in MS care.

PATIENT AND PROVIDER DEMOGRAPHICS

Patients (N = 126)	
Average age (years)	46
Gender	
Female	110 (87%)
Male	16 (13%)
Ethnicity	
African American/Black	61 (48%)
Caucasian/White	55 (44%)
Hispanic/Latino	9 (7%)
Asian/Pacific Islander	5 (4%)
Native American/Alaska Native	1 (1%)
Highest Level of Education	
High school or GED	13 (10%)
Associate's degree	30 (24%)
Bachelor's degree	41 (33%)
Post-graduate (Master's, PhD)	33 (26%)
Professional degree (MD, PharmD, DDS,JD)	3 (2%)
Other	6 (5%)
Health Insurance Status	
Commercial or private plan	83 (66%)
Federal exchange insurance	2 (2%)
Medicaid/Medicare	37 (29%)
No insurance	4 (3%)
Average # years diagnosed with MS	11

Providers (N = 22)	
Physician (neurology)	15 (65%)
Physician assistant	2 (9%)
Nurse practitioner	3 (13%)
Nurse/nurse navigator	1 (4%)
Other	1 (4%)
Gender	
Female	9 (41%)
Male	13 (59%)
Average years involved in MS patient care	14
Average number of MS patients cared for **monthly**	142

RESULTS

Figure 1. Discordances in Patients' and Providers' Perceptions of Quality of Life and MS Treatment Plan Satisfaction

Responded with a **high level of agreement** (Likert 4/5) when asked:

Patients: My care team is fully aware of how MS affects my quality of life and daily living

Providers: I am fully aware of how MS affects my patients' quality of life and daily living

Responded **"somewhat satisfied"** or **"very satisfied"** when asked:

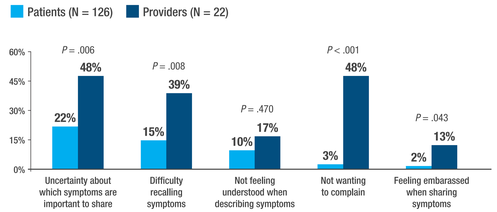
Patients: How do you feel about your current MS treatment?

Providers: How satisfied would you say your patients are with their current MS treatment?

Figure 2. Barriers to Patient-Provider Communication Regarding MS Symptoms

Patients: What barriers do you face in communicating your new symptoms to your MS care team? (Select your top 2)

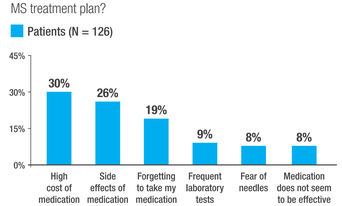
Providers: For patients who do not always communicate their symptoms with you, what do you believe are the barriers? (Select your top 2)



48% of patients responded as **not having any barriers** to communication regarding their symptoms, while **only 4%** of providers said the same

Figure 3. Patient-Identified Challenges in Adherence and Shared Decision-Making

Patients: What makes it difficult for you to stick with your MS treatment plan?



Of the patients who reported barriers to sharing goals, preferences, or concerns about MS treatment with their provider:

- "Care team does not always ask about my goals, preferences, or concerns" 39%
- "Inadequate time to discuss during appointments" 33%
- "My team does not think my goals, preferences, or concerns are important" 22%
- "I am nervous or uncomfortable when talking to my doctor" 6%

Figure 4. Impact of COVID-19 Pandemic on MS Treatment Plan

Patients: Which of the following describes changes you may have made to your MS treatment plan during the COVID-19 pandemic? (Select all that apply)

Providers: What do you believe are the most common shifts in patients' MS treatment plans during the COVID-19 pandemic? (Select all that apply)

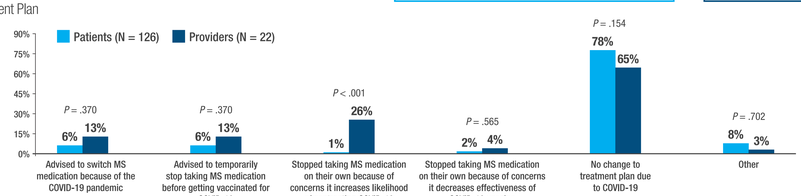


Figure 5. Patients' and Providers' Perceptions of Goals for MS Treatment

Patients: What are your top 2 goals for MS treatment? (Select your top 2)

Providers: What do you believe are your patients' top 2 goals for MS treatment? (Select your top 2)

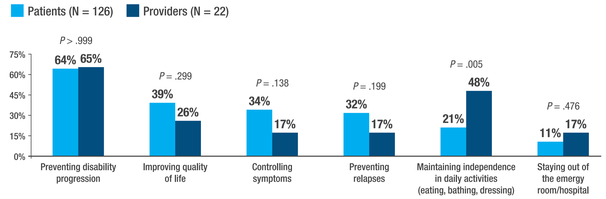


Figure 6. Patients' and Providers' Perceptions of Priorities in MS Treatment Decision-Making

Patients: Which of the following factors are the MOST important for your treatment decision-making? (Select your top 2)

Providers: What factors do you believe are most important to your patients when making decisions about MS treatment? (Select your top 2)

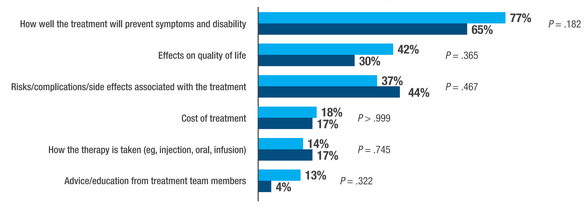


Figure 7. MS Clinic Action Plans and Shared Decision-Making

Patient-Reported Action Plans (N = 65)

- 63% Monitor my MS symptoms more closely and share them with my MS team
- 46% Make sure not to miss any visits (including lab tests and MRIs) at my MS clinic
- 43% Talk with my MS team about my treatment options

When asked, **"How much do you want to be involved in decisions regarding your MS treatment?"** **89%** of patients reported wanting to be quite a bit or very highly involved

Provider-Reported Action Plans (N = 10)

- 80% Talk with my patients about wellness strategies to help manage their MS
- 60% Engage my MS patients more frequently in shared decision-making
- 20% Establish or refine protocols for communication and information exchange with external providers

62% of providers agree/strongly agree with the statement **"Many of my patients would like to participate more often in shared decision-making with me."**

Other Patients' and providers' responses included difficulties in scheduling infusions, delays in DMT doses and starting new DMTs

CONCLUSIONS

We found several discordances in examining patients' and providers' perceptions of MS care. For example:

- Approximately two-thirds of patients reported that care teams were fully aware that MS affects their quality of life (compared to 83% of providers)
- Only 67% of patients reported being satisfied with their MS treatment plan (compared to 79% of providers)
- Nearly half of patients reported that they do not experience barriers to communicating their symptoms to their care team, while only 4% of providers agreed
- While patients and providers were aligned on preventing disability progression as a top goal of MS treatment, nearly twice the proportion of patients reported controlling symptoms and preventing relapses as top goals compared to providers
- Providers were more likely than patients to report shifts in MS treatment plans, including therapy stopping due to increased risk of contracting COVID-19 (26%), temporary pauses in therapy for vaccination (13%), and therapy switching (13%)
- Patients identified several challenges, including:
  - High cost of medication and side effects as the most significant barriers to adherence
  - Inadequate time to discuss and lack of engagement from care teams as the greatest challenges to SDM
- The findings from this initiative revealed essential opportunities to improve MS care; patients and providers identified specific action plans to mitigate these barriers and challenges.

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DISCLOSURES

The study reported in this abstract was supported by an educational grant from Genentech. The grantors had no role in the study design, execution, analysis, or reporting.

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